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Abstract

Jeff Strully, a parent leader from America, states that "the lives of all people in our community are measured by our relationships and connectedness to a place called home where people want to be with us because they are our friends". Human services systems disconnect people with disabilities from their neighbours and communities, and the community comes to have a distorted view of their needs. It becomes harder and harder for families to envision a community-based future for their son or daughter. Strully emphasises the importance of friendships which help to ensure that all people can become active members of the community. He provides examples and concludes that it is time for all of us to work towards connecting people with disabilities to a network of support. **Keyword: Friendship**

Social Integration and Friendship

Jeffrey L. Strully and Kathy Bartholemew-Lorimer

All those things that strengthen relationships between people, that give sense that we need each other and that we are responsible for each other are healthy at this point. - Robert M. Bellah, Habits of Heart

Persons with mental retardation are disconnected from their neighbours and communities. This disconnection is caused and perpetuated by the human services system, which focuses almost exclusively on teaching and training technology as paths to integration in the "normal" society. The typical person with mental retardation is enveloped by the human services structure, which pays little or no attention to the substance of human relationships within community life. Yet relationships with neighbours offer the individual an anchor to the community in the form of personal, vested interest in that person's welfare and fate. The interest and involvement of people in the community provide support to families with handicapped children and enhance the quality of life for all. These relationships also offer hope to communities that compassion for our fellow neighbours will be rekindled and that we will grow to understand and dissolve the differences that divide us.

THE DISSOCIATION FROM HUMAN NEEDS

In our mobile society, adults rarely continue to live in the neighbourhood where they grew up. Our penchant for mobility is not only geographic in nature but economically layered as well. The result is that people become disconnected from their roots, with communities comprising individuals separated from families, families separated from friends, and the "haves" separated from the "have-nots". The actions of bringing people together and of supporting them in personal relationships offer hope for regenerating "community" - a place where citizens get actively involved in the greater good of all, where a newly recognised commonality unites people, and where people step outside their personal pursuits to act in the common good.

Persons with mental retardation, including those with Down syndrome must compensate for their disability in many ways. For such persons, compensating is almost always a struggle, whether it involves moving their bodies, or communicating, or trying to understand. The less obvious struggle involves achieving a "place" in the community. Both the person and his or her family wage this battle. Communities do not readily identify with this struggle because they have little experience with citizens with mental retardation. This inexperience is due primarily to the fact that the human services system regulates practically all activity, or inactivity, in the lives of persons with mental retardation. No family is prepared, either emotionally or experientially, to have a child with mental retardation. They not only do not know how to help such a person into the world, but they are unschooled in what is possible and are therefore vulnerable to whatever services are offered.

All too often, the support provided by human services ultimately swallows the person, taking more and more control, disempowering the families, and leaving communities inadequate to assist. Historically, these services have led to segregation, removing people from community life and citizen involvement. The separation grows over time as families lose the ability to conceive of their child as a community member and as they relinquish more and more power to human services to decide what their child "needs".

The system tests, labels, and categorises a person's eligibility for service. The person is viewed primarily in terms of the disability, which is perceived as a problem. The needs then take the form of structures, and human needs get lost. The structure imposes itself on the life of the person, not merely in service provision but frequently in bricks and mortar in the form of segregation. By the time a child reaches school age, the power and influence of segregation and separation have begun. The child has no playmates and usually

engages in no activity similar to that of a typical child. The child usually shares a classroom, or sometimes an entire school, with other children with handicaps. This classroom or school functions as a neon sign to the typical children that this child is "different" and "devalued" (Wolfensberger, 1975).

Around this time, the family's dynamics begin to shift so that members no longer look at the child as a growing, developing person with wide and diverse human needs and skills. Instead, they begin to see the child in terms of the needs of the disability. In short, families stop thinking about a typical life for their child. Few parents can even dream about a future that looks anything like what they may envision for their other "normal" children, whether it is inviting neighbourhood children to birthday parties, participating in Sunday school class, joining clubs, taking classes, going to ballgames, and so forth. Rather, families begin to see the needs of their child in terms of programs that "professionals" have designed. Such programs are based on an inherent belief that the child does not fit into the "normal" world. The emphasis on teaching and training skills nurtures the pretence that people can earn their way into the typical world when they are "independent" to a certain degree, or when their behaviour is under control. However, exclusive emphasis upon the disability as the problem places the burden of hope for the future on the person with the disability to overcome his or her "disability". The truth is that typical people do not earn their way into the typical world. (To illustrate how far-removed many handicapped persons still are from the community, it was recently reported that Medicaid spent \$4.7 billion in 1985 on long-term care for 146,000 persons in facilities for mentally retarded persons [Braddock, 1987; Braddock, Hemp, & Fujira, 1986J.]

Nevertheless, the human services system has recently made strides in moving people into more homelike environments in the community (Wolfensberger, 1972). However, the focus remains on the habilitation of the disability and *not* on these persons' lives. By the time these individuals reach adulthood, the path is set. Outside their families, with no friends to telephone, to come by, or to care about them, handicapped persons are dependent almost exclusively on the companionship of paid human service workers. They have almost no one in their lives who voluntarily chooses to be involved with them. If the family is absent, there is no human recollection of childhood or of changes in a person over time - only test scores and records. The results can be devastating for the handicapped person's quality of life. The person has become a burden and a commodity in the human services industry. A life that began disadvantaged now must also suffer disconnection from others in general, and discontinuity as the person moves through life from one program to the next run by staff who themselves exhibit high turnover rates.

IMPACT ON THE COMMUNITY

Such reliance on human services affects the community as well. Regular citizens come to have a distorted view of the needs of persons with disabilities. Implications of recent court decisions reflect these distorted views. In both the Baby Doe case (Koop, 1983), regarding life supports for babies born with severe handicaps, and the Bouvier case, regarding a woman with severe handicaps who wanted to fast and be allowed to die, the issue of quality of life was heavily emphasised. If what people can "do" or produce by their levels of independence determines quality of life, many "normal" people would not be judged to have a quality life. However, if quality of life takes into account the people in a person's life who bring worth to his or her life, who enjoy the person and appreciate his or her contribution, and who care what happens to the person, then "quality" is measured differently. If communities do not have the opportunity to experience these kinds of relationships with others and this kind of quality, then the general public may not understand the value of and need for such interactions. Vulnerable persons are then at risk of an impersonal and distanced judgement of what constitutes quality of life.

Typical citizens rarely see handicapped citizens in public places, except in groups of people in which individual identities and personalities do not tend to emerge. Citizens have had even fewer opportunities to get to know a person with a disability on a personal level. Persons with disabilities are the invisible members

of society. As a result, regular citizens come to regard them as the responsibility of human services, as a clinical problem.

A recent story in the *Chicago Tribune* highlighted a prom for a special school (segregated for students with handicaps). The people came to the prom on school buses and returned afterwards to their residential homes. According to the story, the prom gave these disabled youngsters a chance to "practise" their manners and social skills. The article was printed with good intentions: that we should appreciate the efforts of these people and recognise that proms are not always high-fashion events for the able-bodied. However, the gist of the story and the event it described can also be seen as another glaring example of separation. The average person would not have chosen to attend the dance, and it was organised and managed by paid human service workers. Instead of looking at a prom for handicapped persons as a heart-warming event, one could question why it has to be separate. People experience a certain joy and warmth when they come in contact with persons with disabilities. They feel the sincerity of the people and appreciate their efforts. But this contact is almost always in separate, segregated environments, in places where everyone feels safe from the discomfort of people who disrupt the efficiency of our everyday lives. These are places where people do the best they can and where it is okay to make mistakes. But these places should be regularly frequented places in the community, and the safety should be in the form of understanding friends who surround the person. How can we grow to appreciate the efforts and contributions of people with mental retardation if we are never around them? Human services have created the separation, and now families and regular citizens believe it is the way it should be. "Special" events and activities have been fashioned for people to practise for the real thing. Society's attitudes in large part influence a family's reluctance to fully integrate their child into society. Stares and sometimes-cruel questions exemplify the inexperience and misunderstanding of most people. These translate into rejection, and tend to encourage a family to overprotect their child from the real world.

All people depend on others for understanding, help, and kindness. We all hope for dignity during times of weakness and respect during times of vulnerability. Persons with mental retardation have an increased tendency for dependence and vulnerability, but it is something all people experience to varying degrees. We all run the risk that the "dark side" of the human condition will colour our lives or those of other family members, as we grow older. We can look at these conditions as differences that divide, or we can learn about strength that emerges from what appears to be weakness. We can come to recognise vulnerability not as something that divides us but as something we all share; and we can learn that dependence on others is something called experience. In fact, knowing we can depend on others is at the core of happiness and pleasure in our world.

The responsibility to "fit in" should not rest with the person with mental retardation despite the current design of the human services system. It should rest with the general public to include and find a "place" for these citizens in the community. The resulting support to families of persons with disabilities should empower them to choose a life-style that is typical.

IMPORTANCE OF FRIENDSHIPS

It is common to reject or even trivialise personal relationships and their place in people's lives. Yet friendships help to ensure that all people, no matter what challenges they face, can become active members of the community. Community is not just a place where one lives but the people that give one a sense of belonging. Issues of the heart are what make friendships work. They are not commodities that can be mandated or quantified in an individualised program plan. You cannot guarantee that people will want to be with you and enjoy your company, nor can you ensure that people who are "typical" will appreciate you for the person you are. However, friendships, freely given, are at the root of developing competent, caring communities for us all. For too long, people with disabilities have been isolated and lonely.

In considering our own lives, each of us has a ready circle of people to relate to, a network comprising some very close friends and others who are just acquaintances. Our networks may differ in the proportion of close friends to acquaintances, yet each of us has more personal relationships in our lives than do people with disabilities.

Human service workers are largely involved in the lives of persons with mental retardation, sometimes even more than their families. These people are paid to perform a service and are there as part of their job. This is not to infer that a person who is paid to be a human service worker cannot be concerned or caring. This is surely not the case. However, to only have people in your life who are paid to be there is a powerful indictment of our society. Persons with handicaps need folks in their lives who are there because they want a relationship, not because they are obligated to be there.

It is encouraging to note that some positive changes are occurring in our local communities that indicate that we are learning to share with some of our most vulnerable members. The following case studies feature two individuals with mental retardation including those with Down syndrome, who are becoming active community members and friends and neighbours to regular citizens. These stories convey a sense of the human quality that is entering into the lives of the individuals with mental retardation as well as those of the "normal" citizens who are coming to know and care about them.

Case Study: Shawntell

Shawntell's story demonstrates that friendships can and must be developed if all people are to experience community in the true sense of the word.

Shawntell, the daughter of this chapter's first author, is a 14-year-old with mental retardation. She is a beautiful, caring young lady who enjoys sports, listening to music, watching television, going to the movies, riding horses, playing video games, swimming, eating out, and being with her friends. Her friend Tanya is 14½ years old. She is an attractive, intelligent, and caring teenager. The list of things she enjoys includes boys, parties, babysitting, swimming, horseback riding, clothes, music, and her friends.

Tanya and Shawntell met over 6 years ago at their neighbourhood elementary school. Since that time, they have become good friends. They spend time together "hanging out" and doing things that typical friends do. Tanya is not a saint or even an exceptional child. She is just a caring, concerned person who genuinely likes being with Shawntell. She also spends considerable time doing things with her other friends, as does Shawntell.

A strong bond has developed between the girls in the course of their friendship. It is clear from spending time with the girls that they have deep affection for each other. It is relationships such as this that will ensure that Shawntell will be an active member of her community. Relationships, not attitudinal gimmicks (i.e. large puppets and blindfolds), are what create change in our children and in our community.

Shawntell is working to enlarge her abilities in many areas. She is learning to communicate her needs to others by using pictures. She can also tell people what she wants by her gestures, pulls, tugs, and body language. There are those who say Shawntell is non-verbal and cannot communicate. Her friend Tanya disagrees. As Tanya noted with a laugh in a newspaper article on her friendship with Shawntell, "Hey, I know when she's saying, 'Play this cassette.' You can learn her communications, her wishes and desires pretty easily." People can learn to communicate with each other if we only allow them the opportunity as children to learn from one another. If we avoid getting overly concerned about differences and spend more of our time on similarities, we will be better off.

Shawntell is also learning other, practical things such as how to order a simple meal in a fast food restaurant, how to make small purchases, how to play her cassette tape recorder, as well as practising numerous other skills in the regular education environment. Some of these things are "functional", but others are simply fun to learn.

People who do not know Shawntell well might say her quality of life is poor. Some say she could never really have friends, for who would want a friend like her? Others might say that Shawntell would never be useful or productive and will only be a drain on our precious resources. Some persons would ridicule or even tease her, or try to protect her like an eternal child. There are numerous well-intentioned people in our society who would see Shawntell as a handicapped child. But for many people, she is simply their friend, Shawntell. Why should typical teenagers who are bright, articulate, attractive, energetic, and who have wide-ranging interests want to spend time with Shawntell? The reason is simple - they like her! They like her for the person she is and not for who others want her to be. They are not really interested in her label, in her diagnosis, or in the professional jargon that surrounds her. They like her because she is a caring, loving, fun person to be with. They also see the similarities they share, including enjoyment of the Pointer Sisters, the BOSS, chocolate ice cream, the beach, and boys!

About a year ago, Shawntell and her family moved from one state to another. The move was difficult on the entire family, and Shawntell had to start over again developing a network of friends. Relationships do not happen overnight for her, especially with "normal" teenagers who have not previously experienced living, learning, and playing together with her. However, initial connections have been put into place that has the possibilities of developing into friendships.

Shawntell started eighth grade in regular, mainstreamed classrooms this year. Four months after starting school, a new friend of Shawntell's invited her to join the local Girl Scout troop. This was a beginning. Sharing fun and activities with typical girls of the same age has the potential of leading to real friendships for Shawntell. She misses her old friends a great deal, but a new circle of close friends is certain to develop for her.

The power of friendships is incredible to contemplate. When a typical person such as Tanya proclaims her friendship with Shawntell, that makes a tremendous difference in Shawntell's life. It is the Tanya's of our future who will ensure that all citizens are an active part of their community, whether or not they display all the competencies and skills of typical people. Of greatest importance is to be cared about by another human being. If Shawntell is to be an integral member of her community, she will need to rely on her friends who want to be involved with her because they are her friends.

Case Study: Chris

The second author first met Chris, who is now 22 years old, when he lived at Hazelwood (a state institution). He moved out 2 years ago and now lives in a house in a typical neighbourhood with another man who is handicapped. They are cared for by paid staff. About a year ago, the authors arranged for Chris to help out at Harding Pharmacy, a friendly, family-run business that had been in his neighbourhood for a number of years. It was a stable place that gave Chris the opportunity for practical employment and the chance to make special friendships.

When the second author became involved in Chris's life 2 years ago, there was virtually no one who was not paid to be a part of it. Even people who had know him for a number of years were not acquainted with him much more than superficially. Nobody could talk about his childhood, his habits, his personality, or changes they had seen over time - the sorts of things friendships reveal. Of course, there were official records on Chris: the tests he had taken, the goals and objectives he had worked on for 22 years. But these things only

yield fragments of Chris, not the kind of information that would enable someone to be close to him. The author decided that what Chris most needed was people in his life and a place in the community.

Chris has a pleasant personality, a charming smile, and beautiful eyes. He is meticulous about his possessions and wants everything in its place. He is not terribly patient. He likes his life to unfold as he expects it to, and when it does not, he gets upset. Chris does not speak, but his eyes talk, and he has no problem expressing his feelings. At Harding Pharmacy, where Chris stocks the shelves, he cannot physically place the items on the shelf, because he is in a wheelchair, but he decides where the items go and David, the staff person who accompanies Chris to the pharmacy, shelves them. Sometimes Chris is shown a bottle of aspirin and he decides it goes with vitamins. He is shown that he is mistaken - aspirin goes with aspirin. Sometimes he decides he is still right and yells out in anger. Sometimes he is tired when he goes in and does not feel like stocking. He would rather sit and watch the people, smile at the women, and try to get someone to give him something to eat.

All the employees at Harding know Chris well. They help get Chris out of the car into his wheelchair each time he comes. They enjoy his company and appreciate his contributions. Following are some of their impressions of him:

Chris helps us in our store 3 days a week. He puts our stock away and is able to be among the public in this way. Chris has taught me that even though he is in a wheelchair, he can be productive and feel good about himself. People need this type of exposure more. It's so very important that people with disabilities know they have purpose in life and can contribute to the future.

Chris is quite bright. He can learn quickly. He is usually, but not always, co-operative. He has a great sense of humour. We have learned to see past Chris's disability, to see the "person" of Chris. It has been good for us. It has been a learning experience for me. I felt uncomfortable with Chris at first, but after getting to know him, I have no problems.

Recently, the second author met with Mr. Fetter, the owner of Harding, to talk about Chris's future. On her way to the restaurant where they were to meet, she remembered all the times she attended interdisciplinary team meetings while she worked at Hazelwood to prepare team plans for Chris. She would meet with social workers, therapists, teachers, medical doctors, and so forth, people who went in and out of Chris's life. The meetings were professional and impersonal, and rarely addressed the human being, the man, and the real world. The efforts of organised human services tend to focus on skills, behaviours, and bodies. Chris, like all of us, needs to learn things to help him function adequately in this world and opportunities for him to acquire such skills must be provided. But what will make his life truly better and fulfilling is for it to be filled with hope and possibility through relationships with other people. When regular citizens, like Mr. Fetter, get involved, the human services world no longer claims all of the responsibility, and life for Chris becomes more real and worthwhile.

The second author talked to Mr. Fetter about how much the people at Harding meant to Chris and why she had initially approached them. She asked him why he had agreed to let Chris work in his business. Mr. Fetter said he thought it was part of being a good Christian that his church has a tradition of "ministering" to persons with handicaps. He said that in the beginning his biggest concern was how the customers would respond, but that the majority has had no problems at all and no one has ever been nasty. He said Chris was a social person and liked people. Sometimes, however, he said, Chris comes to work angry or upset, and when he does, he lets the employees know it. He said that he thought this was good, since most of us hold back our feelings. But he also added that David, a staff member, is helping Chris to learn to control himself. He said that Chris's future at Harding would become more defined with time. "He'll always need David to be his arms and legs," said Mr. Fetter. This is true, but it becomes increasingly doubtful that the person there to help him has to be David, a paid human service worker.

The second author asked Mr. Fetter how he felt about David occasionally leaving Chris in the pharmacy "on his own" after Chris had finished the stocking. (Chris has stayed with the other employees a couple of times

until his van has come to pick him up.) Mr. Fetter said it had not been a problem. The second author told him that this is done for a reason - when the human services worker leaves, new life comes to relationships between handicapped and non handicapped persons. When David is there, employees and others can think it is nice but that it all has something to do with David, which it does not! Without the presence of the human service worker, regular citizens take more responsibility. They get to know the person better, and it builds confidence in them that this really is no big deal, that they can be with Chris as easily as with anyone. And maybe, just maybe, it will lead to stronger friendships for Chris.

Mr. Fetter asked the second author if she knew that Anita (a Harding employee) took Chris to church once. She said yes, that it was wonderful, and probably one of the few times that a person has voluntarily included him. She told Mr. Fetter that it was preferable for David to help Chris stock, and that he would then leave each day. "If it becomes a problem," she said, "we'll do something." Mr. Fetter said, It wouldn't be a problem. If he chokes or coughs, there are plenty of people to take care of him." The second author told him that she thought he would see things change. "No problem," said Mr. Fetter.

The second author talked with Mr. Fetter about the possibility of arranging for an additional work opportunity for Chris in order to bring more people and variety into his life. Mr. Fetter provided the names of proprietors of four businesses nearby. He said, "They know me. Have them call if they have any questions." He said to give people time to get to know Chris and then everything would be fine. The second author told him that the places that were closest to Harding Pharmacy would probably be contacted first, because Chris would then be more likely to run into some of the same people. Mr. Fetter agreed and said that he shared a deliveryman with Bonnycastle Hardware. "Then," he said, "if Chris goes to Baskin-Robbins for ice cream, he's likely to see a lot of people who know him from one of the two places." The second author explained that this is important because it invests people in Chris's life. If he becomes someone people recognise and know, it is more likely that people will help him if he has a problem. If he gets sick, people might send him a card or drop by to see him. If they have a cookout they might invite him. Or if he were ever at risk of being returned to an institution, maybe people would support him in the community. And no matter who comes and goes in the paid positions in his life, he will have stability in people like Mr. Fetter and others in the community. The more people who come to know and care about Chris, the safer he is and the better his life will be. In Mr. Fetter's words: "People need to get more involved. We need to get government out and let this be the work of citizens and churches." He said I should contact his church about the support services provided to Chris. The second author said, "You should tell them you are the one who is including Chris." The conversation included how nobody can solve all the problems, but that each simple act makes a difference both to the person with a disability and to yourself. Unless regular people come into contact with people like Chris, they do not understand the needs of such persons or what they could do to get involved.

The second author thanked him for agreeing to meet. He said, "The first of many." The second author called Bonnycastle Hardware, talked to Mr Schneider there, and told him all about Chris at Harding. She told him that Mr. Fetter had suggested she call. He readily agreed to have Chris assist in the store.

Chris has been working at the hardware store for 2 weeks now, two mornings a week. He rings the customer bell when people come in. He and David go get coffee for everyone at the local deli. For Chris, the network has begun.

Chris has a future in which people who have come to know him, understand him, and care for him over time surround him. These people are not paid to be in his life but have voluntarily chosen to include him in their lives. The people at Harding Pharmacy and Bonnycastle Hardware are a part of Chris's future.

CONCLUSION

People with mental retardation, including individuals with Down syndrome, are no different from anyone else in their need to be loved, cared for, connected to the people in their environment, and afforded opportunities to share in meaningful activities with people who want to be with them. The stories of Shawntell and Chris support our belief that if enough handicapped and non handicapped persons have experience with integration, if handicapped persons are given a chance to contribute and to share places with others in the community, and if all persons see the importance of friendship, then there is a chance that persons with disabilities will be actively incorporated into our local communities.

Living in the community and being a part of it are not the same. Far too many people living in our local communities are isolated, lonely, and disconnected. It is time that all of us - parents, professionals, and citizens - started thinking about working toward connecting the people that we care about to their communities and to a network of relationships. It is a struggle filled with pitfalls and one that will require us to rethink our values and beliefs. But in this effort, we may truly learn what life is all about and what is really important.

In the end, our relationships and connectedness measure the lives of all people in our community to a place called home where people want to be with us because they are our friends. The challenge is how to make our dreams and visions a reality for all people. It is a difficult and challenging dream, but one that is well worth our efforts. The people we care about deserve nothing less!

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